

CARING FOR PERSONS WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

Current Research Activity

Supported by
National Institute on Aging

NATIONAL INSTITUTES OF HEALTH

May 1998

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CARING FOR PERSONS WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

Overview and Research Priorities

Alzheimer's disease is a major public health problem with up to four million older Americans afflicted with the disease and the annual economic toll approaching \$100 billion dollars. With the aging of the population, the prevalence and cost of AD is expected to rise dramatically. The majority of people with AD are cared for in the community, mainly by family and friends. The progressive nature of the disease, often characterized by disruptive behaviors, makes care especially challenging for family members and professionals alike.

Family caregivers often face a triple jeopardy -- they experience significant emotional stress, frequent physical and financial burdens, and often apathy or hostility from the victims of the disease. These burdens can make caregivers "hidden patients" themselves, in need of outside assistance and support to maintain their own health and functioning. While the burdens of caring for persons with Alzheimer's disease are now well-documented, we are just beginning to examine how social, behavioral, environmental, and technological interventions can make a difference in reducing caregiver stresses and burdens. Additional research is needed to learn how to tailor interventions to different stages of the disease and various caregiver situations.

To understand fully these caregiving dynamics, we also need more information on patterns of care among caregivers in different populations, such as minority group members and caregivers in rural areas. For example, some research suggests significant racial differences in the caregiving process, with blacks showing more benign appraisals of the stressfulness of impairments and of behavioral problems associated with the disease. Yet little is known about caregiving, its consequences, or the effectiveness of strategies to alleviate stresses in other minority groups (e.g., Hispanic or Asian American populations).

Despite the NIA Collaborative Studies of Dementia Special Care Units initiated in 1991, which dramatically expanded the research base in this area, questions still remain about the effectiveness of different types of care in nursing homes and other long-term care settings. Additional research is needed to identify which models and patterns of care are the most effective -- for persons with AD, their family caregivers, other cognitively intact residents, and institutional staff members.

In 1995, the NIA and the National Institute of Nursing Research (NINR) began an initiative entitled Resources for Enhancing Alzheimer's Caregiver Health (REACH). The primary purpose of this initiative is to develop and test new ways to help families manage the daily activities and stresses of caring for people with AD or a related disorder. The REACH project hopes to discover new ways of helping the informal network of family caregivers who provide an extremely important and often difficult service to loved ones and to society.

In an effort to advance and coordinate research on effective strategies for reducing caregiver burden and for promoting quality care for persons with AD, the National Institute on Aging (NIA) has established a free-standing **Burdens of Care-Alzheimer's Disease** unit in the Behavioral and Social Research Program (BSR). NIA encourages research on the following topics:

- **Forecasts of the prevalence of dementia and estimates of the future availability of family and professional caregivers;**
- **Supportive environments and everyday functioning of persons with AD;**
- **Effect of caregiver stresses on caregiver's health and health behaviors;**
- **Social, behavioral, and technological interventions that enhance family caregivers' capacity to deal with burdens of care;**
- **Impact of different health and social service arrangements on persons with AD and their caregivers;**
- **Studies of the economic costs of dementia under different caregiving arrangements and reimbursement policies;**
- **Methodological research to improve assessment of quality of life in cognitively impaired persons;**
- **Caregiving in special populations, such as racial and ethnic minorities and rural populations.**

This document provides brief abstracts of research supported by the Behavioral and Social Science Research Program at NIA. For further information about a specific project, readers are advised to contact the principal investigator directly.

Assessing Caregiver Stress and Burden

PI: Jacqueline Conyers -- University of California Irvine
Title: **Alzheimer Patients' Capacities and Caregiver Assessments**

One aspect of Alzheimer's Disease (AD) that is relatively unstudied is the capacity of the AD patient to be a part of their health care decisions. The patient with probable AD is faced with many dilemmas in life, particularly those pertaining to health care issues. The stages of AD progression – early, middle, and terminal – often overlap and can span several years. Even patients in the early stages of the disease are presumed by many Health Care Providers (HCPs) and caregivers to be unable to take part in a medical discourse, and thus may not participate in their own health care decisions. As AD patients vary in their impairments in the early stages of the disease, the sense of disconnectedness through such disregard often deprives the AD patient of his/her sense of personhood. The aim of this study is to identify and evaluate the views of the HCPs and caregivers' perceptions of the early AD patient's participation in their clinical assessment.

PI: Mary A. Corcoran – George Washington University
Title: **Caregiving Styles of Spouses who Provide Dementia Care**

This FIRST Award examines the processes by which spouses provide dementia care and the ways in which behaviors are managed. The goal of this five-year project is develop a typology of caregiving styles (e.g., the thinking and action processes by which spouses manage the daily care and difficult situations that arise in caring for their family member), and to investigate the relationship between different styles and caregiver well-being. The study uses in-depth interviews and observations in three home visits to 105 spouse caregivers. This study will add to the existing AD caregiving literature by better specifying the caregiving experience and its associated outcomes, and by paying specific attention to the influence of gender and race on management approaches.

PI: Lisa Fredman -- University of Maryland at Baltimore
Title: **Caregivers to the Elderly--Risks and Outcomes of Stress**

This comparative study evaluates caregiver burden among caregivers of elderly persons with AD, frail elderly, and stroke victims compared to a control group. Eighty-five patient-caregiver pairs identified at a clinical setting are included in each of the 4 groups. Patients and caregivers are interviewed 4 times, at six month intervals over a 2-year period. Included in the interviews are standardized measures of stress, burden, depression, health and mental status, and other factors that might be associated with caregiver stress. Analyses evaluate associations between patients' caregiving needs (such

as ADL needs and cognitive impairment), caregiver tasks (performance of ADLs, hours per day provides care), and situational factors (living arrangement, social support) with caregiver stress over time. This study provides useful information on whether and how caregiving burdens are the same or different for persons with AD and other older persons in need of care.

PI: Igor Grant – University of California, San Diego
Title: **Alzheimer Caregiver Coping: Mental and Physical Health**

The project is a longitudinal study of the health consequences of caregiving, which examines how caregiver characteristics such as age and gender affect the relationship between caregiving stressors and cardiovascular-related physiological outcomes. The overarching goal is to examine Alzheimer caregiving by elderly spouses as a model of chronic human stress in the aged. Other aims include examination of: 1) whether vulnerable caregivers differ in their cardiovascular reactivity from nonvulnerable caregivers; 2) whether experimentally introduced stressors predict differential cardiovascular response in these two groups; 3) biological correlates of cardiovascular changes observed during the stress interviews; and 4) whether providing respite to vulnerable caregivers has a selective benefit in terms of cardiovascular responsiveness compared to nonvulnerable caregivers. This is an important study for moving caregiving research out of the purely psychosocial realm to the biobehavioral realm, where pathways linking stresses to poorer cardiovascular health outcomes can be identified, and potentially modified by targeted interventions.

PI: Jennifer M. Kinney -- Bowling Green State University
Title: **Caregivers' Burden Over Time/A Stress and Coping Approach**

This is a longitudinal study of 200 spouse caregivers of persons with Alzheimer's disease or a related dementia. Caregivers are assessed monthly for six consecutive months to determine the stability of stressors in their situations. Aspects assessed include: mastery, daily hassles associated with caregiving, appraisals of the most significant stressors in each of five areas of caregiving, coping attempts, perceptions of change in the caregiving situation over time, and physical and mental health adjustment. Care recipients' cognitive and functional status are re-evaluated periodically. This focused study, which collects data at relatively short intervals, provides important information on the most difficult aspects of caregiving and how spouse caregivers cope over time.

PI: Rebecca G. Logsdon – University of Washington
Title: **Quality of Life in Alzheimer's Disease**

The goal of this investigation is to assess longitudinally quality of life (QOF) in individuals with Alzheimer's disease and to identify variables that influence quality of life in this population. Based on symbolic interaction and transactional theories of adult development, this study has two aims: 1) to develop and administer an empirically based, psychometrically sound, and clinically relevant measure of quality of life that can be administered to community-residing AD patients and their family caregivers, and 2) to obtain longitudinal data on changes in quality of life in 200 community residing AD patients evaluated every six months over a three-year period. By identifying factors that are related to quality of life, this study will assist in the development and evaluation of interventions to maximize AD patients' quality of life.

PI: Marcia N. Neundorfer – Case Western Research University
Title: **Depression and Agitation in AD – Effects on Caregivers**

The purpose of this study is to examine the effects, over time, of depressive and agitation symptoms in persons with AD on depression in their caregivers, while controlling for patient cognitive and ADL status. Further, this study proposes that patient depression and agitation lead to caregiver depression through the mediating effect of caregivers' perceptions of their caregiving experience. Specifically, it is proposed that these patient symptoms increase caregiver negative perceptions (e.g., overload), decrease positive perceptions (e.g., uplifts), and lead to caregiver depression. Therefore, this study will add to understanding of the effect of AD patient depression and agitation on both caregiver perceptions and caregiver depression, guiding interventions toward critical patient symptoms and caregiver management of their own reactions to them.

PI: Margaret A. Perkinson – Philadelphia Geriatric Center –
Friedman Hospital
Title: **Dementia/Cardiac Symptom Management by Family
Caregivers**

The FIRST award research project will (1) compare the processes of symptom recognition, evaluation, and management by family caregivers of frail elders to findings in the self-care literature and (2) identify predictors of family caregivers' responses to symptoms of their frail relatives under varying conditions. Family caregivers' response to symptoms (i.e. their strategies and criteria for identifying and assessing symptoms and the factors influencing their decisions to self-treat, seek medical care, seek alternate forms of care, or take no action), will be examined and compared to the findings

reported in the self-care literature. The impact of socio-cultural factors will be examined by comparing African American and White caregivers in terms of available resources, information sources, and attitudes. The effect of type of illness underlying the care-receiver's symptoms and the subsequent character of those symptoms (e.g., where symptoms are physical or psychological) will be examined by comparing family caregivers' reactions to symptoms of dementia and cardiovascular disease. Insight into the factors influencing caregivers' responses to symptoms of their impaired relatives may facilitate a more collaborative relation between caregivers and health professionals.

PI: Ann M. Steffen -- Veterans Affairs Medical Center, Palo Alto
Title: **Analyses of Social Support in Dementia Caregivers**

This postdoctoral fellowship research uses an existing longitudinal data set of family caregivers of persons with AD. The investigator will examine whether perceptions of social support predict caregiver depression and life satisfaction; whether caregivers experience deterioration in support over time, and factors that contribute to changes in perceptions of support. Analyses focus on predictors of change in social support perceptions and interactions over a two-year period. The study provides data on the nature of social support processes over time, their relationship to depression, distress, and perceived burden, and possible target areas for interventions with caregivers.

PI: Peter P. Vitaliano -- University of Washington
Title: **Caregiver Mental Health and Alzheimer's Disease Outcomes**

The investigator's research to date demonstrates that caregiver risk (personality, health, distress) and resource (coping, social supports) variables at baseline predict subsequent caregiver burden, patient activities of daily living (ADLs), and nursing home placement. This project extends the earlier work by questioning couples twice (15-18 months apart) over 3 years. Three hypotheses are tested: 1) Caregivers who are most vulnerable to distress at baseline will report the most burden at follow-up; 2) persons with AD living with caregivers who are the most vulnerable to distress and have the fewest resources at baseline, will have the lowest ADL levels at follow-up; 3) caregivers who are more vulnerable to distress at baseline will, over time, admit their AD spouses into nursing homes at a higher rate than caregivers who are less vulnerable to distress. Each analysis controls for patient ADL levels and caregiver burden at baseline. This study provides information that may be used in psychological interventions with caregivers.

PI: Sharon M. Wallsten – Duke University Medical Center
Title: **Elder Caregivers, Care Receivers, and Their Interaction**

This study of spousal caregivers and care receivers examines patterns of interaction, social support, and psychological well-being of caregivers compared to noncaregivers as a function of income and race. Questionnaire data are collected in respondents' homes from both noncaregivers and caregiving dyads three times over a three year period. In addition, caregiver-care receiver interaction is videotaped. The study includes objective as well as subjective physical health measures of caregivers, assessment of chronic problems of patients as well as activities of daily living, and a measure of daily stress that applies to both caregivers and noncaregivers. Certain instruments and methods employed throughout the study may eventually be appropriate as diagnostic aids in evaluating problems in dyadic interactions or in other factors that could be modified to ease the burden of caregiving. Results from this project are relevant to intervention programs to aid elderly caregivers and care-receivers in the home setting. By including care receivers with and without AD, the study provides information on how AD caregiving may differ from caregiving for other older persons in need of care.

Identification and Amelioration of Caregiver Abuse

PI: Gregory J. Paveza – University of South Florida
Title: **Aggression and Violence in Community Based AD Families**

This is an epidemiologic retrospective study of Alzheimer families to identify individual, family, and interactive factors that are associated with changes in conflict resolution, including the development of aggression and violent behavior among individuals with AD, and family members providing care to those persons. Specific goals include the description of conflict resolution as AD progresses; determination of the specific rates of occurrence for various forms of conflict resolution; determination of specific patient and caregiver characteristics that place families at risk for aggression and violence; and the specification of characteristics that tend to prohibit the development of violence or aggression in families caring for a member with AD. This study will provide important insights into levels of abuse and aggression in some caregiving relationships.

PI: Linda R. Phillips – University of Arizona College of Nursing
Title: **Intervention for Abuse of Aging Caregivers**

This project focuses on abuse of aging female caregivers (wives and daughters both over age 55) perpetrated by an elder for whom they are the primary, in-home, family caregiver. The project has four aims: 1) to test the long-term effectiveness of a community-based intervention administered by a registered nurse promotora team; 2) to test a theoretical model that proposes structural, situational, and interactional factors to explain domestic abuse; 3) to test the efficacy of the intervention and the explanatory power of the model in two ethnically distinct groups – Anglo Americans and Mexican American; and 4) to describe the natural history of abuse in the long standing relationships between aging women in both cultures and their elderly spouses or aging parents. Methodological approaches include the use of field experiments, causal model testing, and qualitative methods. Findings from this research will assist in the design of primary prevention of caregiver abuse.

Alzheimer's Care in Minority Populations

PI: Robert M. Emerson -- University of California Los Angeles
Title: **Caregiving Practices in Hispanic and Anglo Families**

This project examines ethnic and gender differences in caregiving practices that spouses employ in the home to take care of and manage the person with AD. It also explores family caregivers' consideration of and possible turn to formal caregiving strategies, including support groups, respite and in-home care, day care, and institutionalization. The research employs qualitative in-depth interviews at six month intervals over a two year period with a final sample of 60 Hispanic and Anglo Alzheimer spousal caregivers. Participant observation focused on gatekeeping and entry processes at agencies that either assess family caregiving needs and link family caregivers with formal services, or that directly provide such services, is also used. The project provides important comparisons between Hispanic and Anglo patterns of caregiving and potentially contributes to the development of culturally sensitive social and psychological interventions.

PI: Sue Levkoff -- Harvard Medical School
Title: **Health Promotion for Demented Ethnic Minority**

This minority aging center includes a complementary set of research, intervention, educational, and outreach activities designed to understand how ethnic minorities and their caregivers experience and cope with Alzheimer's disease. The center focuses on African-Americans, Chinese, and Puerto Ricans. The research core examines how cultural factors influence older persons' recognition and response to symptoms of dementing disorders, caregivers' response and coping, and assessment and response by the health care community. The intervention core adapts three existing interventions designed to reduce excess disability among elderly with dementia and to enhance the coping capabilities of caregivers. The education core includes the provision of education and outreach to staff of health and social agencies, the public, state legislators, academic faculty, and medical students. This project contributes to greater awareness within the medical community of the specific stresses and burdens experienced by different ethnic minorities.

PI: Wayne C. McCormick – University of Washington
Title: **Long Term Care Utilization in Japanese – Nikkei Long Term Care Project**

The Nikkei Long Term Care Project is a population-based, cross-cultural study of long-term care use among elderly Japanese Americans who are part of a larger study on the epidemiology of dementia. The primary goal of the study is to analyze models of determinants of long-term care in an Asian-American population across different disabilities. Focusing on cognitive function generally, and dementia diagnosis in particular, investigators are now assessing the independent role of cognitive impairment in nursing home placement of minority populations. Data on preferences and attitudes, family support structure, physical health, and other socio-cultural variables will also be collected. The investigators are using in-depth qualitative methods, including interviews and participant observation of long-term care sites, to further elucidate the determinants of long-term care use among Japanese-American elders. This is one of the first population-based studies to examine preferences and attitudes for long-term care in this understudied population.

PI: Baila H. Miller -- University of Illinois
Title: **Gender and Race in Care of the Cognitively Impaired**

This research, based on in-person structured interviews with 225 spouse caregivers of persons with AD in Chicago, examines the influence of race and gender on adaptation to caregiving by blacks and whites. The goal of this project is to identify race and gender differences in caregiving stressors, resources, and adaptation (satisfaction vs. distress)

among spouse caregivers. The analysis evaluates whether race and gender influence all the components of adaptation or whether racial differences are greatest in exposure to secondary stressors (e.g., financial strains), personal resources (e.g., religious involvement), and use of informal and formal supports. Also evaluated is whether gender differences are greatest in selected types of stressors (e.g., the type of tasks performed), selected resource areas (e.g., preparation for caregiving, or in ways in which emotional distress and satisfaction are expressed. By considering gender and race together in one study, this study extends theories of gender socialization and research on black support systems and provides the basis for more refined policy options for potentially disadvantaged populations.

PI: Jacobo E. Mintzer -- Medical University of South Carolina
Title: **Caregiving for Hispanic Alzheimer's Patients**

This is a five-year descriptive cross-cultural community survey of family members caring for persons with AD among 100 each of African American, Hispanic, and white American caregivers. Measures include prevalence and type of symptoms of depression and anxiety in family caregivers, the ability to tolerate the patient's mental health symptoms (measured as the duration and the severity of the illness prior to seeking professional help and degree of caregiver's subjective burden), knowledge and utilization of community support services, household composition, degree of sharing of caregiving responsibilities, beliefs about caregiving obligations, the caregiver's perceived social support, and caregiver's coping strategies. Socioeconomic factors and degree of acculturation are assessed. This community-based nonclinical sample provides important information on how caregivers from different ethnic groups are coping in the community and adds to the accumulating knowledge base for appropriate and accessible community programs.

PI: Rosalie F. Young -- Wayne State University
Title: **Cultural Impact on Caregiving Outcomes--Alzheimer's Patients**

Although blacks and whites have comparable rates of Alzheimer's disease, blacks are less likely to be placed in institutions than whites. This longitudinal study examines attitudes, behaviors, and caregiving stress in relation to institutionalization among 600 persons with AD and their care providers, half black, half white. Caregivers are interviewed four times and outcomes, including institutionalization, for the persons with AD are tracked. The investigators hypothesize that black persons with AD are less likely to be placed in institutions even when their caregivers experience comparable stress, because expectations for home-based care are stronger than among white caregivers. The project provides important information on racial differences in institutionalization.

PI: Elena S. H. Yu -- San Diego State University
Title: **Caregiving in Shanghai, China**

This Shannon award provides pilot investigation for a study of caregiving in a Chinese population, using data from a representative sample of 5,055 older adults. This group of adults was originally surveyed from 1987 to 1989 as part of the Shanghai Epidemiologic Study of Alzheimer's Disease and Other Dementias. The investigators rescreened the 1987 sample and identified their caregivers. The sample includes both demented and non-demented older people in need of care. The care receivers and care providers are interviewed 3 times regarding caregiver burden, intolerance, and psychological well-being and associated factors. This project increases knowledge about the trajectory of Chinese caregiving and also provides useful information for future studies of Chinese American populations.

Interventions for Reducing Family Caregiving Burden

REACH (Resources for Enhancing Alzheimer's Caregiver Health)

The primary purpose of REACH is to carry out social and behavioral research on interventions designed to enhance family caregiving for Alzheimer's disease and related disorders. Six research projects have been funded through cooperative agreements with the National Institute on Aging and the National Institute of Nursing Research. These projects will focus on characterizing and testing the most promising social, behavioral, environmental, or technological interventions for enhancing family caregiving, particularly with minority families. Funds have also been set aside for a Coordinating Center.

PI: Louis Burgio – University of Alabama at Birmingham
Title: **Skill Training for African American and White Caregivers**

Researchers will focus on the common needs of African American and White caregivers of a family member with AD. One aim is to evaluate the effects of a caregiver training and intervention package that is designed to increase the caregiver's ability to manage the care recipient's behavioral problems, as well as increase the ability to cope with daily stressor through training in problem solving skills. This intervention will be compared with a minimal support condition which will receive telephone calls. A second aim is to assess the effects of the program on care recipient outcomes including behavioral difficulties and quality of life. A third aim is to investigate any differences between African American and

White caregivers in skill acquisition and performance; and any difference in care recipient's responsiveness to the intervention.

PI: Robert Burns – University of Tennessee at Memphis
Title: **Providers and Alzheimer's Caregivers Together (PACT): A Primary Care Model for Enhancing Family Caregiving**

This study examines ways in which primary care physicians can decrease the burden of family caregivers of individuals with AD. Three interventions will be evaluated: *information and referral care* simulates usual care of dementia patients such as providing information about dementia and making referrals; *behavioral care* in which caregivers receive counseling sessions about behavior management; and *enhanced care* which will build on the previous approaches by teaching behavior modification strategies to decrease caregiver stress. Caregiver outcomes to be assessed include: caregiver burden, depression, life satisfaction, perceived health status, and utilization of health care for caregiver and care recipient.

PI: Carl Eisdorfer – University of Miami
Title: **Family-Based Interventions for Caregivers**

Investigators are conducting a study of the effectiveness of several innovative interventions that focus on the family. These approaches combine psychosocial and engineering solutions to the problems confronted by Cuban American and White American caregivers. The study will randomize caregivers, care recipients and their families to one of three conditions: in-home intervention involving visits by a therapist to improve communication, promote well-being, and ease distress; the in-home intervention in combination with a Computer Telephone Integration System; and a minimal support condition which will receive telephone calls. Caregiver outcomes include caregiver burden, distress, perceived social support, and caregiver satisfaction. An important contribution of this study is the design of interventions appropriate for both Cuban American and White American populations.

PI: Dolores E. Gallagher-Thompson – Stanford University
Title: **Treatment of Distress in Hispanic and Anglo Caregivers**

This study aims to improve the psychological functioning of Hispanic and Anglo women who are the primary caregivers of family members with dementia. Female caregivers will be assigned to one of several interventions including a minimal support condition which will receive telephone calls, an enhanced support group, or a psychoeducational class teaching skills on how to cope with stress, frustration, anger, and sadness. The researchers will compare the programs and how they work for different groups. Primary outcome measures will examine symptoms of depression and anger, caregiver functioning

including coping responses and pleasurable activities, and various dimensions of caregiver burden and social support. Measures to help explain the changes brought about by the intervention will also be obtained and will include self-efficacy, characteristic style of expressing anger, length of time as a caregiver, and, in the Hispanic group, the level of acculturation. The results of this study will extend the theoretical and clinical understanding of the caregiver experience to one group of minority families whose proportion is steadily increasing in this county.

PI: Laura N. Gitlin – Thomas Jefferson University
Title: **Home Environmental Skill-Building Program for Caregivers**

Researchers will evaluate the benefits of a specialized home-based program for individuals caring for a family member with AD. This intervention will instruct caregivers in using their environment effectively to minimize functional decline and behavioral difficulties experienced by the person with dementia. A sample of caregivers from diverse cultural and economic backgrounds who reside with and care for someone with middle or moderate dementia will be enrolled in the study. Anticipated outcomes include increased use of environmental strategies, improved home safety, improved caregiver well-being and self-efficacy, and decreased excess functional dependency and problem behaviors in the individual with dementia. This intervention is standardized and reproducible and yet responsive to the individualized needs of caregivers and impaired persons.

PI: Diane M. Mahoney – Boston University
Title: **TLC Telephone System for Alzheimer's Family Caregivers**

The focus of this study is to examine the impact of an automated telecommunications system on reducing caregiver stress related to disruptive behaviors of people with AD. The system is called Reach for TLC (Telephone-Linked Care): Caring for the Caregiver. Reach for TLC is a 24-hour system that speaks over the phone to caregivers using a computer controlled human voice system. This innovative system will monitor the caregivers' stress and health status weekly and make recommendations and referrals if necessary, as well as provide other services. The study will be conducted at five sites, with many African-American and Hispanic caregivers included in the samples. Caregiver outcomes to be assessed include caregiver distress, depression, perceived health status, caregiver role, competence, and mastery.

PI: Richard Schulz – University of Pittsburgh
Title: **REACH Coordinating Center**

The Coordinating Center will work with the five intervention sites and the NIH to carry out research on interventions designed to enhance family caregiving for Alzheimer's Disease. The research team will be responsible for 1) identifying and compiling

background information regarding family caregiver research, 2) working with the other investigators to identify, select, and psychometrically evaluate measures to be used in a common data set, 3) developing a standardized data collection protocol and data management system, and 4) collecting, editing, storing, and analyzing all shared data. Other tasks include providing technical assistance, monitoring recruitment and retention of study participants, and providing training to assure consistent implementation of the common protocol. In addition, researchers will develop and implement a quality control system for data collection, prepare and develop all data forms, produce and update a manual of operations, and devise plans for dissemination of information resulting from these studies.

PI: Brooke S. Harrow – New England Research Institutes, Inc.
Title: **Cost Impacts of Enhancing Alzheimer’s Disease Caregiving**

The purpose of this ancillary study, supported by the National Institute of Nursing Research (NINR), is to examine the cost impacts of REACH interventions designed to enhance family caregiving for Alzheimer’s Disease. Using secondary data analysis, this project will extend the REACH analysis of outcomes to look at impacts across interventions, using measures of health care utilization, caregiving costs, and outcomes collected for the core REACH data set. Specific aims include: 1) measuring cost of community-based care across ethnically and geographically diverse populations; and 2) comparing cost-effectiveness for the two interventions with technology components. This project will contribute much needed data on the impact of caregiver interventions on caregiver health services utilization.

Other Research on Interventions for Reducing Family Caregiving Burden

PI: Michelle S. Bourgeois – Florida State University
Title: **Interventions to Change Caregiver and Alzheimer's Disease Patient Outcomes**

This 5-year intervention study assesses the relative efficacy of a treatment program that provides caregivers either with skills necessary to change the problem behaviors of their spouse with Alzheimer's disease, with an intervention which teaches them to manage their own affective responses to caregiving challenges, or with an intervention which combines both treatment strategies. These three treatments are compared with wait-list controls in which contact with trainers and general information are provided in "friendly visits." Following psychosocial assessment of caregivers and cognitive and behavioral assessment of persons with AD, 80 caregiver/patient dyads were randomly assigned to one of the four conditions. The groups are compared on several caregiver and care recipient outcomes including caregiver expression of stress, burden, self-efficacy, anger, and depression, and frequency of care recipients' behavioral excesses and deficits. This project provides important information on which to base the development of effective psychosocial interventions with caregivers.

PI: Michelle S. Bourgeois – Florida State University
Title: **Increasing Effective Communication in Nursing Homes**

Improving the communication between residents and nursing home staff should have positive effects on the quality of life of nursing home residents, and could potentially enhance staff job satisfaction as well. The purpose of the proposed study is to increase the rate and quality of staff-resident communicative interactions and decrease the frequency of resident disruptive behavior. Conducted in 8 nursing homes across two geographic sites, the intervention in this study includes a combined prosthetic memory aid and staff management intervention. Specific aims include 1) assessment of the efficacy of intervention treatment for increasing the frequency of interaction; 2) assessment of the effect of the intervention on the quality of interaction; and 3) assessment of the effects of the treatment on disruptive behaviors. This project will determine the effectiveness of an intervention aimed at interaction enhancement, and the role of communication in quality of life and health outcomes for both patient and staff.

PI: Patricia F. Brennan -- University of Wisconsin – Madison
Title: **Supporting Home Care Via a Community Computer Network**

This study builds upon an earlier project which developed a computer network to link caregivers of persons with AD and other disabling diseases with professionals and peers to provide support when needed. Findings from the earlier study showed that most caregivers learned to use the network and that components of the network that fostered interaction with other caregivers were used most often. The communication component was used more than either the decision-making component or an interaction component. Caregivers reported liking the ability to use the network at times of day that were convenient to them. This project seeks to determine the link between use of the computer network and formal service use by analyzing daily logs kept by the caregivers, records of each caregivers' use of the network, and transcripts of the public communications posted in the networks' open electronic bulletin board.

PI: Paul M. Gertman -- Lazo, Gertman & Associates, Inc.
Title: **An Electronic Community for Alzheimer's Caregivers**

The overall objective of this Phase I Small Business Innovative Research (SBIR) grant is to design an interactive multimedia advanced telecommunications system targeted at the medical, social, and psychological needs of primary and secondary caregivers of patients with Alzheimer's disease and other dementias. This system will network caregivers, patients, physicians and others into an "Electronic Community for Alzheimer's Caregivers" (ECAC), and includes a videoconferencing link to providers and support groups, a diary module, an automated medical encounter system, an educational module, and a psychological diagnostic module permitting providers to detect issues which require professional intervention. Aims include the development of the ECAC model through evaluation of the biopsychosocial needs of patients, families and other health providers through focus groups, and development of an experimental research design for the Phase II effort to evaluate the results of the ECAC approach. This product is designed to empower and ease the burden of home-based caregivers through access to educational, referral, and outreach services.

PI: Laura N. Gitlin -- Thomas Jefferson University
Title: **Dementia Management: Home Intervention for Caregivers**

This study is a three-year project to test the effectiveness of a home-based intervention for individuals caring for and residing with a family member with moderate impairment from AD. The overall goal of the intervention is to enhance the caregiver's ability to integrate information about environmental influences into his/her problem-solving process, resulting in an improved ability to manage the behavioral or secondary symptoms of dementia. A two-group, randomized experimental design targeting 250 primary caregivers is used to test the effectiveness of the intervention. The treatment group participates in a 5 visit home-based intervention while the control group does not. A three month post-test evaluates the immediate effect of the experimental program to reduce caregiver stress and

improve patient behavior. A six month follow-up measures incidence of nursing home placement, caregiver health behaviors, and caregiver expansion of management skills to new problems. The project yields important information about the benefit of home-based support services including the effectiveness of environmental manipulations in the home to modify behavior.

PI: Robert Hawkins – Care Trak
Title: **Where Did Grandma Go? Locating Wanders with Dementia**

Wandering by patients with Alzheimer's Disease represents a serious problem, often placing persons at risk of injury and forcing families to institutionalize family members. The goal of this Small Business Innovative Research (SBIR) grant is to evaluate a new technology for controlling wandering that does not reduce independence nor is it restrictive. The technology, the *Care-Trak System*, consists of four components, including a miniature transmitter worn by the patient, door alarms, portable perimeter alarms, and a mobile locating device for finding wanderers. The first study will evaluate the benefits and limitations of the system by pilot-testing with caregivers and persons with dementia. The second study will survey family caregivers and professional care providers to assess their judgment of the system's effectiveness. This project will reduce the burden of caregiving for some families and permit the AD patient to remain longer in the home.

PI: John V. Hobday – Perceptual Engineering, Inc.
Title: **CD-ROM/Internet Alzheimer's Caregiver Education**

The goal of this Small Business Innovative Research (SBIR) grant is to develop a CD-ROM Internet resource for caregivers and families of individuals with Alzheimer's disease. The focus at Phase I is to develop the multimedia components of the first ten of what will be an eventual fifty Most Commonly Asked Questions about Alzheimer's Disease. Focus groups will identify, test, and validate the process and selection of the fifty questions, and evaluate program effectiveness. The prototype will be created as a shell, enabling its reuse for future versions focused on other diseases. Phase II will develop content and programming for additional modules, including the remaining 40 questions. Distribution of this product is directed at individuals, rural and urban health clinics, physician offices, hospitals, nursing homes, and community access sites such as public libraries, community centers, and places of worship.

PI: Douglas Holmes -- DMH Associates, Inc.
Title: **Computer-Based Intervention Re: Demented Elderly**

This Small Business Innovative Research (SBIR) project implements a computerized communication system which automatically calls persons according to a pre-established

schedule, addresses each person by name, and refers to specific topics germane to each person such as particular appointments or specific drug regimens. In addition, the system supports incoming calls using pre-recorded speech segments to respond to questions asked by the caller following a decision tree protocol. The system can support up to 24 simultaneous telephone calls. The system is seen as a cost-effective substitute for in-person telephone monitoring of older persons, including those with AD and related disorders, permitting monitoring and reassurance functions at very low cost.

PI: A. Blair Irvine – Oregon Center for Applied Science, Inc.
Title: **Interactive Video: Education for Dementia Caregivers**

The goal of this Small Business Innovative Research (SBIR) project is to develop a touch-screen interactive multi-media education/referral program to be used by informal caregivers of dementia patients in clinics or senior resource centers. The touch screen kiosk will offer the caregiver the choice of a needs assessment with guided education, or a menu of topics, including local resource information. Modules of interest include general education, care management issues, caregiver skills, problem solving, caregiver self-care, and resource referral. Information will be automatically printed for the user. In Phase I, a prototype program will be developed providing education and local referral, which will be evaluated for use in hospital resource centers. In Phase II, development will be completed on the educational and needs assessment modules, while expanding the education and referral components of the prototype, and will include a randomized clinical trial to evaluate the efficacy of the system.

PI: Abbey C. King – Stanford University
Title: **Exercise, Functioning and Stress in Women Caregivers**

This study provides one of the first tests of a physical activity regimen designed to enhance caregivers' physical functioning and performance, decrease disability, and improve health-related quality of life. The objectives of this study are to 1) determine the effectiveness of a home-based moderate-intensity physical activity program in promoting significant increases in physical performance and functioning in older women caring for a family member with AD; 2) evaluate the efficacy of the physical activity regimen for promoting changes in day-to-day functioning and well-being variables; and 3) evaluate the effects of family caregiving on ambulatory blood pressure and heart rate responses as stress indicators. The study design is a one-year randomized trial in which women caregivers aged 50-75 will be randomly assigned to one of two conditions: supervised home-based physical activity training, or non-exercise control (music/relaxation). The public health implications of this research are substantial, in light of the increasing number of older women joining the ranks of family caregiving, and the critical role they play in the delivery of care.

PI: Mary S. Mittelman – New York University Medical Center
Title: **AD Caregiver Well-Being: Counseling/Institutionalization**

The NYU Aging and Dementia Research Center has been investigating the effects of counseling and social support on spouse-caregivers of Alzheimer's disease patients since 1987. Investigators have demonstrated that counseling and social support can postpone institutionalization and maintain caregiver mental health. The goal of this project is to use the longitudinal database to study the natural course of AD caregiving and to test the efficacy of several innovative enhancements to the intervention. Spouse-caregivers of demented patients will be randomly assigned to treatment or control group to continue to assess the effect of the intervention on cost of caregiving and quality of life for all study subjects. This study will make a substantial contribution toward reducing the emotional and financial cost of AD to families and to society as a whole.

PI: Steen A. Parl – Signatron Technology Corporation
Title: **Low Cost Patient Locator System for Geriatric Wandering**

This Phase II Small Business Innovative Research (SBIR) grant is implementing and testing a novel, low-cost radio location system for rapidly locating patients with cognitive disorders who are at high risk of wandering. In Phase I the investigators demonstrated the accuracy of the location system and will conduct field testing of hardware during Phase II. The system consists of a small Patient Locator Unit (PLU), carried by the patient, which transmits a signal to a network of base stations in response to a page. The study will determine the system's technical performance, reception by patients and caregivers, and the circumstances under which the device can be used. The strength of this inexpensive system is that it permits greater independence to Alzheimer's patients and their caregivers, and may delay the need for institutionalization.

PI: Karl Pillemer -- Cornell University
Title: **Social Network Interventions for Dementia Caregivers**

This project assesses the benefits of a social support intervention for caregivers of persons with AD. Social support is provided by persons who have experienced the caregiving situation. Study participants include 240 caregivers of persons with Alzheimer's disease recruited from a large dementia screening program that serves both urban and rural populations. Caregivers are randomly assigned to one of three conditions: a peer-led support group, support enhancement home visits by a volunteer caregiver, and a control condition. Data are collected in a pre-intervention interview and three post-intervention interviews over one year. Qualitative data on the group and dyadic interactions are also collected. Caregiver well-being, levels of interpersonal stress, and appraisals of social

support are evaluated. This project provides information on the efficacy of using status-similar individuals to increase caregiver well-being, and also determines whether the intervention is related to maintaining the person with AD in the community.

PI: Daniel Syed -- Atlantic Microsystems, Inc.
Title: **Advisor for Caregivers to Alzheimer's Patients**

This goal of this project is to produce a personal computer-based Advisor for Caregivers of Alzheimer's and other Demented Patients (ACAP). The ACAP system comprises an expert system, an information system, and a care resource database. It is intended to promote an understanding of dementia-related disease processes, provide an overview of the medical, custodial care, financial, and legal problems normally encountered, and identify specific sources of national and local assistance. The system may be updated easily, and simplicity and flexibility are emphasized in the program for ease of use by caregivers of all ages. A marketing approach has been devised and is currently being implemented, with use by both families and professional caregivers envisioned.

PI: Steven H. Zarit -- Pennsylvania State University
Title: **Mental Health of Caregivers of the Elderly**

The primary goal of this project is to assess the benefits of day care services for family caregivers of older people with dementing illnesses. A secondary objective is to study patterns of service use. Relatively little research has investigated the benefits and drawbacks of various interventions for family members. In particular, day care and respite services have been proposed as a critical link in community-based long-term care, but evidence of benefits for the mental health and well-being of the caregiver is limited. Drawing upon a general stress process model, day care is expected to affect the amount of time caregivers have available for other activities, leading to change in caregivers' appraisals of stressors and overall well-being. Experimental subjects include 200 principal family caregivers of dementia patients participating in a New Jersey program of day care. A control sample, matched on key variables such as kin relationship, living arrangements, race, and SES, will be drawn from a comparable population in another state. The results of this project will further our understanding of the effects of the provision and amount of respite on caregivers' appraisals of stressors and well-being.

Institutional Care for Persons with Alzheimer's Disease

Special Care Units for Alzheimer's Disease

Ten collaborative studies were funded beginning in 1991 to examine the nature of Special Care Units for dementia and to evaluate their impact on nursing home residents, family members, and nursing home staff. These ten studies share a common database for describing SCUs and their impacts.

PI: Denis A. Evans -- Rush-Presbyterian-St Luke's Medical Center
Title: **Longitudinal Study of Four Types of Alzheimer's Disease Special Care Units**

This longitudinal study is comparing care for persons with Alzheimer's disease in four settings: (1) usual inpatient nursing home units, (2) Alzheimer's disease inpatient nursing home units, (3) usual adult day care units, and (4) an Alzheimer's disease day care unit. Data are collected on physical function, cognitive function, behavioral problems, use of physical restraints, medication use, and falls, injuries, and hospitalization at regular intervals over a 36-month period.

PI: Leslie A. Grant -- Univ. of Minnesota, School of Public Health
Title: **Special Care Units in Minnesota Nursing Homes**

This study describes and classifies care arrangements in nursing homes for persons with dementia, examines outcomes associated with the care arrangement types, and tests the effectiveness of a biography-construction exercise performed by family members shortly after the admission of a relative in nursing homes throughout Minnesota. A variety of outcome measures are obtained for residents with dementia, cognitively intact residents, family members, and nursing home staff.

PI: Douglas Holmes -- The Hebrew Home for the Aged at Riverdale
Title: **Differential Costs and Inputs for Special Care Units**

The goal of this study is to determine whether there are differential service inputs associated with SCU care in comparison with non-SCU care, and with different subgroups among demented residents in 12 nursing homes. Data are collected on the service provider, the service recipient, and the nature, date, and time of the service. Cost effect and cost benefit modeling are used to address policy concerns related to calculating case mix based reimbursement rates.

PI: Nancy G. Kutner -- Emory University
Title: **Budd Terrace SCU Care Model: Multidimensional Analysis**

This is a study of a single Special Care Unit located in an intermediate care facility. Ethnographic observation of resident and staff behavior are analyzed. Of particular interest is the circadian behavior changes in AD patients referred to as sundowning-the

onset or exacerbation of agitation, restlessness, panic, intensified disorientation, and verbal or physical outburst in the afternoon or evening. Sundowning represents a significant management problem, and the control of behavioral outburst requires labor-intensive and emotionally taxing attention from families or other care providers. Outcome measures include resident behavioral disturbances; family satisfaction, involvement and morale; and staff job satisfaction, involvement and support.

PI: M. Powell Lawton -- Philadelphia Geriatric Center
Title: **A Stimulation Retreat Program for Alzheimer's Patients**

The purpose of this project is to examine the effect of individually tailored intervention which prescribes more stimulation or less stimulation according to the patient's needs in two identical 50 bed Special Care Units. The impact of the intervention is assessed by means of direct testing of residents, rating by staff members and family members, and the direct observation of behavior. Resident outcome measures include cognitive functioning, health nutritional status, ADLs, psychopathology, behavior, participation in activities, socialization, and affective status. Family outcomes include well-being, attitude, and number of visits.

PI: Joel Leon – Project Hope – Bethesda, MD
Title: **National Evaluation of Special Care Units Project**

This project examines outcomes for a nationwide sample of dementia patients recently admitted to Special Care Units and to standard nursing homes. Standardized samples of 600 persons with AD entering each type of care setting are evaluated at time of placement and six months later. A significant family member for each resident also provides information. Outcome measures for residents are length of survival, health status, hospitalizations, catastrophic reactions, agitation, cognitive functioning, falls and injuries, physical restraints and psychotropic drugs used, incident reports in the medical record, and level of participation of family activities. Outcome measures for families include satisfaction with care, caregiver stress, involvement in terms of visits, and care planning.

PI: David A. Lindeman -- University of California – Davis *and*
Rush Presbyterian St. Luke Medical Center
Title: **Alzheimer's Special Care Units - Longitudinal Outcome Study**

This longitudinal study measures the outcomes and effectiveness of Alzheimer's disease Special Care Units for residents, family caregivers, and staff. Data are collected on 172 persons with AD in SCUs and 172 persons with AD in non-SCU nursing homes in California 5 times over two years. Questionnaires to nursing home staff members and

family caregivers, direct observation of residents and nursing homes, and review of medical charts are the primary means of data collection. Analyses relate demographic information, nursing home characteristics, problem behaviors, physical and pharmacological restraints, health, functional and cognitive status, caregiver stress and satisfaction, staff stress and satisfaction, and activity programming.

PI: Rhonda J. V. Montgomery -- University of Kansas

Title: **Special Care Units: Impact on AD Residents, Family, Staff**

The goal of this study is to construct measures to reliably assess various elements of Special Care Units and programs for residents with Alzheimer's disease and to investigate the impact of each element on residents, family, and staff. The five elements of SCUs to be studied are staffing, training, environment, policies, and program. Data are being collected from 900 nursing home residents residing in 100 nursing homes (50 with SCU, 50 without, but matched on other characteristics) in North Carolina (24), Michigan (42), and Washington (44). Data are also obtained from key administrators, staff, resident charts and records, and through questionnaires to family members and staff who provide direct care to residents in a longitudinal design over an 18-month period. Outcome measures include resident physical functioning, social behavior, problem behavior, mobility, time use and use of restraints; family involvement with the nursing home and satisfaction with care; and staff turnover, attendance patterns, job satisfaction, and morale.

PI: John N. Morris -- Hebrew Rehabilitation Center for Aged,
Boston, MA
Title: **Evaluating a Family Partnership Program in Special Care
Units**

This study evaluates a formal Family Partnership Program between families and staff in Special Care Units in comparisons of 234 residents in each one of a matched pair of nursing homes with SCUs in Massachusetts, Rhode Island, and New Hampshire. The program is randomly assigned to one of the pair of nursing homes. The Family Partnership Program is comprised of six modules: Resident Assessment and Care Planning; Family Resource Center/Network; Family Caregiving; Enriched Visitation, Involvement in Activities Programming; and Special Care Community Caregiving. Outcome measures for residents include changes in cognitive status, mood, involvement, social response patterns, physical functioning, and health. Family members outcome measures include satisfaction with care, level and nature of involvement, and morbidity.

PI: Philip D. Sloane -- University of North Carolina
Title: **Outcomes of Alzheimer's Special Care Units in Five States**

This study examines outcomes of nursing home care among persons with Alzheimer's disease and related disorders in all nursing homes and Special Care Units in Kansas, Maine, Mississippi, South Dakota, and Wisconsin. The study states are currently participating in HCFA's Multi-State Nursing Home Case Mix and Quality Demonstration Project (CMQD), a five-year longitudinal study of all nursing home residents in those states which is collecting standardized data on all residents every year. Both demented and non-demented patients are evaluated on physiologic function, self-care, affect and well-being, behaviors, and freedom from restraints. SCU characteristics associated with better resident outcomes are identified in terms of administrative characteristics and policies, staff characteristics and behaviors, and physical characteristics of the SCUs.

Associated SCU Research Studies

PI: Margaret P. Calkins – Innovative Designs
Title: **Environmental Assessment Protocol for Special Care Units**

Despite evidence of the potential therapeutic effects of the physical environment for people with dementia in long-term care settings, facilities have limited options for learning how to create more supportive environments. As a result, few facilities are incorporating those environmental features cited as important in the research literature. This Small

Business Innovative Research (SBIR) grant will develop an environmental self-assessment protocol, providing an inexpensive means to conduct facility-specific assessments. The protocol will be derived using both rational and empirical techniques. First, an expert panel of consultants will participate in the development and refinement of an exhaustive list of environmental attributes posited to be therapeutic to cognitively impaired individuals, which will be translated in the assessment protocol. Secondly, this preliminary protocol will be administered in 60 SCUs. Third, the data will be subjected to factor analysis to empirically derive the conceptually meaningful items for inclusion in the final protocol. Facilities using the product will send the raw data to I.D.E.A.S., Inc. for analysis and will receive a report accompanied by information necessary to guide the design of appropriate environmental modifications.

PI: Jeanne A. Teresi -- Hebrew Home for the Aged at Riverdale
Title: **Impact of Special Care Units in Nursing Homes**

This is a 12-month longitudinal study of SCU impact on cognitively impaired residents and non-cognitively impaired residents living in residential health care facilities in five Northeastern States. SCU program attributes are delineated and defined and subsequent analyses focus on the relationship between each attribute and patient outcomes. 960 patients (320 non-cognitively impaired, 320 cognitively-impaired non-SCU, and 320 SCU) are selected from among new admissions at 32 sites. Outcome measures include a number of standardized measures of mental status, ADL, depression, behavior patterns and morale, collected at two points in time during site visits. Information is collected through chart reviews with key informants (usually nurses) and patient interviews. Multivariate analyses are used to identify direct and indirect relationships among the data.

PI: John R. Zeisel – Hearthstone Alzheimer Care
Title: **Design Criteria for Alzheimer's Special Care Program**

In the field of dementia care, professionals and researchers consider an appropriate physical environment to be an effective therapeutic element in the delivery of quality care for individuals with Alzheimer's disease and related dementing illnesses. Current research suggests that in the next decade ten thousand or more special care units (SCUs) and day care programs will be established with therapeutic design features that are intended to better support these residents. This project's long-term objective is to develop a system of design criteria and tools that care settings, including homes, adult day health centers, residential care, and nursing care facilities, can use to create therapeutic environments for such individuals. The project will test and modify the therapeutic efficacy of a set of design criteria that the principal investigators developed over the last two years through a literature review and expert consensus process. The project will produce a manual and computerized data collection forms, which can be customized by each user so that they can complete a post-occupancy evaluation and design process for a therapeutic care

environment. Families, facilities, and design professionals can purchase this system to evaluate existing, or to renovate or create new, therapeutic environments.

PI: Sheryl Itkin Zimmerman -- University of Maryland *and*
University of North Carolina

Title: **Aged with Dementia: Facility Effects on Health Outcomes**

This study describes and compares the characteristics of a diverse set of 59 nursing homes which contain a mix of patients similar to those in U.S. nursing homes generally. Analyses assess the relationship between nursing home characteristics (such as staff/resident ratio and resident involvement in activities) and health outcomes including morbidity, health care use, and mortality for residents with AD during the year following admission to the nursing home. The project also examines whether nursing home characteristics influence functional outcomes such as cognition, independence in activities of daily living, and behavior for survivors one year after admission, and whether the nursing home characteristics which are beneficial for demented residents also benefit non-demented residents. The study includes 6 special care units for persons with AD.

Residential Special Care

PI: Denis A. Evans -- Rush-Presbyterian-St Luke's Medical Center

Title: **Longitudinal Study of Day Care in Alzheimer's Disease**

Many persons with Alzheimer's disease require custodial rather than skilled care and many families wish to delay nursing home placement as long as possible. Respite care in general and adult day care in particular may lessen the burden on caregivers and encourage continued family caregiving. Investigators on this project have two specific aims: 1) examine the relationship between adult day care, the use of other health-care services, and entry into a nursing home; and 2) examine whether day care use is associated with beneficial changes in health and functioning of both the client and the primary caregiver. This longitudinal study will include 450 people, half users of day care and half non-users, over a three-year period of observation. Measurement of multiple health variables, and other measures of physical and cognitive function, will occur at six-month intervals. This project will determine how adult day care can improve caregivers' quality of life and lessen the stress associated with caring for a family member with AD.

PI: Philip D. Sloane -- University of North Carolina
Title: **Alternatives to Nursing Home Care for Alzheimer's Disease**
and
PI: Sheryl Itkin Zimmerman – University of Maryland at Baltimore
and University of North Carolina
Title: **Medical and Functional Outcomes of Residential Care**

Nationally, nearly three million older persons are housed in long-term care settings. Until recently, most were in nursing homes. However, the past decade has witnessed rapid growth in residential alternatives to nursing homes, including board-and-care homes, assisted living and adult family care homes. The Collaborative Studies of Long-Term Care, a joint project of the University of Maryland at Baltimore and the University of North Carolina at Chapel Hill, will systematically study the structure and outcomes of this important health care area. This four-year project, which began in 1996, consists of two NIA-funded studies that will share a common data base and analysis coordinating center. Over 15 investigators, representing health services research, epidemiology, biostatistics, nursing, social work, sociology, anthropology, and health economics, are involved in the study team. The study's goals include: 1) description of the structure and process of residential care in four states, differentiating between small homes, larger board-and-care style homes, and assisted living facilities; 2) to compare health and functional outcomes over one year for persons in various residential care and nursing home settings; and 3) to examine the relationships between the structure/process of care and outcomes/cost. Elderly residents in participating facilities will be studied, with a special focus on those with Alzheimer's Disease.

The Financial Cost of Alzheimer's Disease

PI: David A. Lindeman -- University of California Davis
Title: **Costs of AD Special Care Units**

This study of the costs of Special Care Units for Alzheimer's disease includes data on the nature and duration of services rendered to individuals as part of the development of a patient-specific cost-of-services measure. The goal of the project is to quantify the costs of care among SCU demented, non-SCU demented, and non-demented residents in 25 Special Care Units and 15 skilled nursing facilities in California. Other goals are to identify subgroups with different levels of service needs, to compare the cost-effectiveness of SCU vs. non-SCU care for demented patients, and to use a cost-benefit approach to evaluating the extra inputs assumed to be associated with the SCU approach.

PI: Dorothy P. Rice -- University of California, San Francisco
Title: **Cost of Formal and Informal Care of Alzheimer's Patients**

The goal of this study is to estimate the current direct and indirect costs of Alzheimer's disease, based on longitudinal data on the utilization and costs of medical, social, and informal services for institutionalized and non-institutionalized persons with AD. Data were collected in California from approximately 100 non-institutionalized persons with AD and their caregivers, and 100 institutionalized persons and their caregivers. Information is based on formal medical and health care expenditures such as physician services, laboratory tests and other diagnostic procedures, drugs and prescriptions, home health care, other medical personnel, hospital and nursing home care; formal social service expenditures such as senior center services, adult day care, nutrition programs, transportation services; informal care provided by family members and caregivers such as assistance with household chores, mobility and basic activities of daily living; and societal costs such as productivity losses of both victims and caregivers. The costs to the nation of AD will be estimated using the data collected in California.